

## National Family Caregiver Support Program Resources

### Caregiver Cooperatives – Voluntary Respite Services



### Summary

A paucity of funds did not hamper a group of determined caregivers from creating an empowering “self-help” initiative to address the needs of caregivers for respite care. Drawing from their experiences as mothers swapping babysitting with other moms when their children were young, caregivers participating in a Drop-In Respite Program partially supported by an Administration on Aging National Family Caregiver Support Program grant, formed a Caregiver Cooperative, which operates a caregiver-volunteer respite program that “earns and buys” respite time with the Co-op. The Asian Community Center of Sacramento Valley, Inc. (ACC) developed the ideas and energy of this group of spouses and adult daughters to achieve an innovative approach to expand respite services for older adults and their caregivers.

### Background

In partnership with the local Area Agency on Aging, ACC established a Drop-In Respite Program in July 2001. The program is open to everyone regardless of race and ethnicity, though three-fourths of its participants and their caregivers are Asians of Japanese, Chinese, and Filipino descent. The program operates once a week; providing up to 5 hours of recreation, socialization, physical exercise, and mental stimulation to frail elders with Parkinson’s Disease and Alzheimer’s and other dementias. At the same time, respite provides caregivers a chance to “take a break” to tend to their own needs, run errands, or just have a moment to relax. For a majority of the caregivers, participating in a formal long-term care program such as the ACC Drop-In Respite is a first-time experience. Not surprisingly, initial reluctance to enroll loved ones was common, consistent with the documented underutilization of formal long-term care services among Asian Americans in many communities across the country.

As with other underserved communities, gaining the confidence and trust of Asian family caregivers by addressing their language and ethno-cultural programming needs has been critical to the success of ACC’s Drop-In Respite. Special attention is made to develop activities with Asian themes. Bilingual and bicultural volunteers and staff are recruited and trained. Within a year following its inception, many caregivers recognized that respite once a week was not enough to meet their needs; they requested an additional day of programming.

Without additional funds, however, augmenting Respite was not possible. Caregivers began talking among themselves and proposed an innovative solution to address their needs: a solution that did not encumber the resources of the existing respite program and was affordable for them. The time-honored tradition of neighborhood moms exchanging babysitting to give each other a chance to run errands, make and get to appointments, and spend more time with their spouses was the approach they proposed. As one Co-op founder puts it, “We used to do it with other moms when our children were young. Why not swap looking after our elderly parents with other caregivers at ACC Respite?” This “self-help” approach gave rise to the Caregiver Cooperative.

### The Co-Op Approach

The Caregiver Cooperative reinforces Asian values of reciprocity and fiduciary responsibility which are part of being a part of a community. In this community of caregivers, values of volunteer exchange that engenders ownership and accountability are the cornerstones of the Co-operative. Weekly respite services were extended by an additional day (Friday), which was available only to caregivers willing to participate in the exchange. For family caregivers unable to contribute volunteer time in the Co-op due to poor health, employment,

and other obligations, recruiting others to volunteer on their behalf is an option. Co-op members volunteer once a month, equivalent to one respite day (5 hours per month), in exchange for a full month of Friday respite. A calendar is set-up for Co-op members to sign-up for respite duties and divvy up responsibilities. Several individuals specialize in arts & crafts activities, leading group singing, leading food preparation activities or assuring participants have one-on-one time during the day. Members are also responsible for raising funds to cover material and other program costs. Caregivers participate in ACC's annual Yard Sale to raise funds by selling baked goods and white elephants. Co-op members also solicit donations from local merchants, families, and friends.

As an advisory group and sounding board for the Co-op, the Caregiver Council was established for all Co-op members, ACC staff, and other caregivers. The Council provides oversight to the Friday Co-op, as well as helps plan, develop, and improve respite services and other caregiver programs at ACC. Issues that come up in the program are brought to the attention of the Council for discussion. Council meetings are also used to orient new Co-op members and volunteers as well as to provide on-going training and technical assistance for the Co-op. The Council meets quarterly though ACC Drop-In Respite staff is available to oversee Co-op operations and attend to issues that come up.

## Discussion

The Caregiver Cooperative challenges the traditional notion that respite is an opportunity for renewal where caregivers must break away from the care recipient. Interviews conducted with Co-op members in April 2004 indicate otherwise. According to one caregiver,

volunteering in the Co-op is "respite in itself." It keeps him occupied and enjoying the interaction with everyone. Caregivers take pleasure in watching their family members enjoy themselves and participating in activities they did not realize their loved one could do. "This is a good arrangement. It makes respite care affordable and volunteering once a month is a small price for the benefits to both the senior and the caregiver," comments one of the Caregiver Co-op's volunteers.

The Co-op is an ideal introduction for first-time users of community based long term care services for the elderly. Active participation in the program assuages the guilt caregivers often feel when they leave a loved one in the care of others and alleviates concerns about leaving family members who are often confused in a new environment. As Co-op members, family caregivers experience first-hand what the ACC respite program is all about and by working collaboratively with other volunteer caregivers, have control over how the program should be run. Activities developed in the Co-op provide caregivers with creative ideas on ways to physically and mentally stimulate their loved ones at home. Most importantly, the Caregiver Cooperative promotes a sense of community by creating a network for caregivers who support each other. The cooperative approach heightens caregivers' receptivity to community long term care services for the elderly in part because their small group experience reduces isolation, provides a sense of normalcy and socialization with regard to caregiving skills, behavior and expectations among peers. As well, it has bolstered family member support, making the ACC Drop-In Respite program a success.

*Information provided in this fact sheet was adapted from materials submitted by the Asian Community Center of Sacramento Valley, Sacramento CA..*

## FOR MORE INFORMATION

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